

Relevant Core Values and Recommendations from Tiger Team August 19 letter:

- Patients should not be surprised to learn what happens to their health information.
- The provider-patient relationship is the foundation for trust in health information exchange.
- Providers are responsible for ensuring the privacy and security of patient information but may delegate functions to business associates if done in a trustworthy manner.

NEW core value: Transparency about information exchange practices is a necessary component of establishing credibility with patients. In achieving greater openness and transparency for patients, we need to balance the need to give patients complete information on how their information is shared while at the same time providing information in a form that is manageable for patients to read and understand.

Consistent with these core values and previous recommendations, we have the following additional recommendations:

1. Providers are responsible for being open and transparent with their patients about how their data is exchanged. This involves providing the Notice of Privacy Practices required by HIPAA (subject to the additional recommendations below), but providers also should be encouraged to discuss information exchange practices with patients, particularly where there is a new significant development such as "indirect exchange" through a business associate that triggers consent per our previous recommendations (such as an HIO) or when the provider's EMR is shared with an OHCA (see further recommendations below).
2. With respect to the HIPAA Notice of Privacy Practices (the "NPP"):
 - a. Providers should provide a layered notice - a short summary of information sharing policies and activities should be required for all patients. This "summary notice" should indicate how to obtain more information.
 - b. A more detailed notice for interested patients should also be readily available.
 - c. The notice should not only be in plain English but should be written at a reading level that most of a covered entity's patients would understand and presented in compliance with applicable laws with respect to language and disability.
 - d. The notice should ideally cover current and anticipated exchange activities in lieu of merely describing what the law permits.
3. Where there is "indirect exchange" through a business associate that triggers consent per our previous recommendations, providers' notice to patients should not be buried in the HIPAA NPP – it should be easily distinguishable and understandable by a patient. Such notice should also be layered.
 - a. All patients should receive a brief summary description of the indirect exchange model, including the name(s) of the organization(s) with legal responsibility for managing the indirect exchange model and the purposes for which information can be shared by or through the model.
 - b. Per previous recommendations, notice of the provider's intent to participate in "indirect exchange" should take place before the patient's record leaves the control of

the provider.

c. Patients must have an ability to obtain more detailed written information about the indirect exchange model, such as the names/identities of other participants. Providers may provide this directly to patients or rely upon the exchange to provide the information (i.e., providers should use materials provided by the exchange or may direct patients to the exchange for more information).

4. With respect to organizations like OHCA and integrated delivery networks:

i. All patients should receive summary information about the provider's participation in such an organization and that generally describes how other entities that are part of or share records with the OHCA will have access to the patient's information. As with the notice required for participation in an indirect sharing arrangement, it should be distinct and not be buried in the HIPAA notice.

ii. Patients should have an ability to obtain more detailed written information, including a list of the other entities in the OHCA have access to their information. The provider may provide this information to patients directly or refer the patient to easy-to-find organizational resources.

5. ONC should require federally funded HIOs and Regional Extension Centers to develop and implement public education plans regarding their information sharing policies and practices.

Example of summary notices for OHCA & HIOs:

HIO: We send an electronic copy of your medical record to the state health Information organization, which makes your data available to other healthcare professionals. We also use a gateway for electronic submission of prescriptions, which keeps a copy of your medications profile. If you want to learn more details about how we perform electronic exchange of data, you may request a copy of our Detailed Information Exchange Description, which can also be found at this web-site: <http://...>

OCHA or other organization:

If named: We are part of IntegratedHealthSystems, which has a shared electronic medical record system that allows the other clinicians and hospitals of IntegratedHealthSystems to have access to your record to ensure that your treatment is informed by the best available information. More information is available at (web site name).

If small practice participates in OHCA or other organization but doesn't use its name: Your health information is in the Electronic Health Record System that IntegratedHealthSystems (IHS) shares with us as well as with its own clinics and hospitals and with other non-IHS providers that also have access to your record to ensure that your treatment is informed by the best available information. More detail is available at (web site name)